Quality of life in children with hydrocephalus

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(no conflicts of interest)
Outline:

1. Basic principles of measuring health/QOL
2. Specific challenges in measuring QOL in children
3. Broad overview of what we currently know about QOL in pediatric hydrocephalus
4. Speaker introductions
What is “health”? 

• “A state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.” (WHO, 1948) 

• multidimensional
Definitions

What is “quality of life (QOL)”?

- multidimensional
- subjective and based on the perception of the individual
- can include objective information (i.e., what an individual can do) and the individual’s subjective appraisal of their QoL

Eiser & Morse. J Dev Behav Pediat 2001
Pediatric Issues

Challenges in measuring QOL in children with conditions of the brain:

• Not all children can meaningfully answer questions about their QOL
• How do you define QOL for an infant?
• How do you define QOL for a child who is severe neurologically compromised?
Pediatric Issues

Not all children can meaningfully answer questions about their QOL

- **Proxy responders have limitations**
- **Can proxy respondents ever provide a true picture of QOL?**
What do we know about QOL in pediatric hydrocephalus?
What do we know about QOL in pediatric hydrocephalus?

I. Overall QOL in hydrocephalus
What do we know about QOL in pediatric hydrocephalus?

Overall QOL in hydrocephalus:

• Lower QOL scores on average than the general population
• HUI utility score = 0.58
  • control Canadian children = 0.89
  • ELBW teens = 0.87
  • adults with Alzheimer = 0.58
• But QOL varies widely...
What do we know about QOL in pediatric hydrocephalus?

II. Proxy responders in hydrocephalus
What do we know about QOL in pediatric hydrocephalus?

Surgeons’ global ratings of the child’s health is not very accurate....

Pearson correlation

- physical health 0.65
- social health 0.55
- emotional health 0.22
- cognitive health 0.51
- overall health 0.35
What do we know about QOL in pediatric hydrocephalus?

Parents underestimate the QOL of the child...
What do we know about QOL in pediatric hydrocephalus?

III. The major QOL issues in hydrocephalus
What do we know about QOL in pediatric hydrocephalus?

The major, self-identified QOL-related issues in pediatric hydrocephalus:

- Cognitive difficulties
- Behavior difficulties
- Headaches
  - 60% have chronic headache
  - 10-20% severe
What do we know about QOL in pediatric hydrocephalus?

The major self-identified concerns into adulthood:

- depression (42%)
- not living independently (40%)
- lack of drivers license (30%)
- unemployment (40%)
- substance abuse (9%)
- denial of health insurance (70%).

Gupta et al. J Neurosurg Pediat 2007
What do we know about QOL in pediatric hydrocephalus?

IV. The determinants of QOL in hydrocephalus
What do we know about QOL in pediatric hydrocephalus?

The major determinants of QOL in pediatric hydrocephalus:

- Etiology of hydrocephalus
- Seizures
- Shunt complications
- Social, economic, family factors
What do we know about QOL in pediatric hydrocephalus?

Etiology of hydrocephalus:

• myelomeningocele, preemie IVH ➔ worse physical QOL

• longer initial hospital stay ➔ worse overall QOL
What do we know about QOL in pediatric hydrocephalus?

Seizures:

• 30-50% prevalence of epilepsy
  ➔ worse QOL
What do we know about QOL in pediatric hydrocephalus?

Shunt complications:

• shunt infection
  → worse QOL

• multiple shunt revisions
  → worse QOL

• longer hospital stay for shunt complications
  → worse QOL
What do we know about QOL in pediatric hydrocephalus?

Social, economic, family factors:

- lower family income → worse QOL
- less parental education → worse QOL
- remote communities, unmet service needs → worse QOL
DETERMINANTS OF OVERALL QOL

**BIOLOGY:**
- Etiology
- Medical comorbidities

**SOCIOECONOMIC:**
- Family income
- Resource access

**HEALTH CARE:**
- Early treatment
- Early complications

**FAMILY/COMMUNITY:**
- Family functioning
- Geographic location

**FAMILY STRUCTURE:**
- Number of parents
- And siblings

QOL of child with hydrocephalus
What do we know about QOL in pediatric hydrocephalus?

V. Summary
What do we know about QOL in pediatric hydrocephalus?

QOL varies widely in pediatric hydrocephalus

The determinants of QOL also vary and only some are potentially mutable by us

The high-yield areas:

- Reduce infections and other complications
- Define the true benefits of endoscopy on QOL, if any
- Improve community service access/delivery
- Improve transition into adulthood
Speakers
Speakers

Dr. Paige Church:

• Assistant Professor of Paediatrics at the University of Toronto
• Director of the Neonatal Follow Up Clinic at Sunnybrook Health Sciences Centre and the Developmental Behavioral Paediatrician in the Spina Bifida Clinic
• board certified in both Neonatology and Developmental Behavioral Pediatrics with interest in the long-term outcomes of children either preterm or those with congenital anomalies
• Title: “Developmental effects of hydrocephalus on the fetal brain and outcomes in premature babies”
Speakers

Dr. Mohit Bhandari:

• Canada Research Chair in Musculoskeletal Trauma
• Professor and Chair, Orthopedic Surgery, McMaster University
• Associate Member, Department of Clinical Epidemiology and Biostatistics, McMaster University
• Title: “Advantages of evidence-based treatments: changing the philosophy of a field and identifying good research”
Thank you...